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ABSTRACT

Assessment and treatment implications of family therapy for mentally retarded individuals are examined. Parental reactions to initial diagnosis are noted as are special problems exhibited by parents (such as parental inadequacies and emotional problems) that require intervention. The critical nature of diagnostic interpretation is emphasized, and the need for supportive family counseling at this point is stressed. Three areas for treatment intervention are explored: (1) within the developmental life stages of families with a retarded child, (2) through the hierarchical structure of these families, and (3) inside the central triangle (mother, father, disabled child) of the retarded child's family. Case studies illustrating each type of treatment intervention are offered. Diagrams of family dysfunction commonly found in families with mentally retarded children are presented. The professional's role in trying to foster functional intrafamilial relationships through restructuring the family hierarchy and family role assignments is considered. Eleven references are listed. (CL)

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FAMILY THERAPY AS A TREATMENT MODEL FOR FAMILIES WITH A MENTALLY RETARDED CHILD

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The current emphasis on rights and individualization of services for the mentally retarded child has brought new challenges and opportunities for professionals who serve them. A dramatic turnabout in philosophy and approach to serving these children has occurred in the past decade as human service professionals continue to work to establish quality services intended to meet specific children's needs. Many of these efforts are now grounded in the local community, and more children are consequently able to remain within the family unit. The resulting impact of such changes in emphasis upon family life has attracted the increasing interest of clinicians.

Human service delivery systems and educational and child development facilities have continued to seek the development of models of effective diagnostic and therapeutic services to meet the developmental needs of each child. These models provide for both acute and chronic needs, address normal as well as abnormal developmental issues, and are holistic in view. The whole developmental schema of the mentally retarded child is considered within a process focusing on the child's family situation.

CONSIDERATIONS FOR ASSESSMENT

Several general considerations are necessary for the assessment of mentally retarded children and their families. Wolfensberger (1967) has reported that a diagnosis of mental retardation may precipitate for parents and other family members a period

of acute crisis accompanied by denial, anger, shock, and sorrow. The self-esteem of the parents may be at stake, and initial family responses toward a mentally retarded child may involve guilt or rejection of the child as well (MacKeith, 1973). Given the heightened anxiety and defensiveness of these parents, communication problems may emerge between parents and professionals during these times of crisis. Information may be distorted in the face of this anxiety, and reality testing for this situation becomes an important element in the assessment process. Other identifiable risks for the clinician are the possibility of being sentimental and over-involved, as well as that of focusing excessively upon the deficit itself rather than upon the whole child.

At the time of assessment, the diagnosis becomes the initial step in the ongoing process of treating the child in his family system, and thus helping the mentally retarded child develop to his fullest potential. The rationale for this is that, of the many systems in the child's environment, the family system is still the primary agent in social, psychological, and cognitive development (Waisbren, 1980). A mentally retarded child's presence in a family may generate much in the way of special needs, and the entire family is directly affected by this, demanding that the clinician apply the concepts of systems theory to understand family dynamics. The understanding of such families is not a simple matter of establishing cause and effect, as numerous causes and effects are continually operating in concert. Causes

are effects and effects become causes in the cyclical interactional pattern of family relationships. Family interactions then slowly evolve out of these often-repeated patterns of behaviors and communicational responses between family members.

The clinician treating a family with a retarded child must be able to observe the family and each of its members from a perspective that respects and understands the fluid nature of the family system. The frustration or anger expressed by a parent may not simply be reactions to current behavior, but may instead be part of an unfolding story of family interaction both inside and outside the family system. Family systems theory and family therapy are the categories for this treatment approach, but an even broader view of systems theory is required by the professional working with a mentally retarded child and his family. The systems-based theoretical perspective blended with the wealth of knowledge already available on mentally retarded children and their parents and siblings provides a foundation for development and utilization of an effective intervention strategy.

The parents of the retarded child may also exhibit their own special problems requiring assessment and intervention. There may be parental inadequacies exhibited, for example, by a mother whose development is also delayed. Parental emotional problems, either chronic or situational, may be impacting upon the general nuclear environment. Immature parents may exhibit poor impulse control and be at-risk, or be frankly abusing the child. Indivi-

dual parent problems, such as poor resolution of personal grief, alcoholism-related difficulties, and personal growth issues will need to be identified. Waisbren (1980) reported that parents of a retarded child may even acquire a new identity as new role requirements are forced upon them. These parents may experience symptoms of psychological stress, a sense of loss, ongoing crisis and a decrease in self-esteem (Fowler, 1968; McMichael, 1971). Many researchers have focused their studies on the family unit to better understand the mentally retarded child as well as the initial reaction of other family members to the child. Mandelbaum and Wheeler (1960) observed that such parent reactions as loss of self-esteem, shame, depression, ambivalence and defensiveness should be considered part of a normal process for parents of a retarded child. The theoretical hypotheses of Schild (1971) support the idea of such parent reactions being crisis-oriented in nature.

Diagnostic interpretation to the child's parents offers an opportunity for the family to join in the assessment process, commenting, articulating questions, and giving helpful input and feedback to the professional. Interpretation of the child's difficulties may focus upon practical problems but will certainly speak as well to the critical issues of the acute reactions of the parents, child, and siblings which may impede implementation of the professional recommendations, for upon this implementation may rest the question of whether this child will reach his fullest potential. Immediate supportive counseling may be needed to

realign parental expectations and aid the parents in focusing on any positive developmental prospects. Acceptance of reality factors at this point may help the parents to avoid such problems as rejection of the child, feelings of irrational guilt, conflicted management of the child, and the inappropriate fixing of blame. Weber and Parker, in a 1981 study, reported professionals and parents alike agree that the awareness, knowledge, and understanding by the parents of their child's condition are the most important factors in their positive adjustment to the disability. There is a high level of consensus among both groups that the earlier this knowledge and diagnostic information is provided, the better the parental adjustment will be.

TREATMENT IMPLICATIONS

Specifically, three areas for treatment intervention will be explored: first, within the developmental life stages of families with a retarded child; second, through the hierarchial structure of such families; and third, inside the central triangle of the retarded child's family. For purposes of this discussion, each will be presented separately, but it is plain that this separation is artificial. Each area is inextricably blended with the others.

Developmental Life Stages

Until recently there have been two primary notions regarding the ways families manage their feelings in relation to their retarded child. Olshansky (1962) identified "chronic sorrow" as the family's reaction, an experience of prolonged existential pain and depression that is never fully resolved but which the

family learns instead to endure. Others have looked at the management of these feelings as a series of developmental crises to be resolved (MacKeith, 1973). Families with a retarded child will periodically need intervention because of the specific developmental issues with which they are dealing. Crisis-precipitating events such as the birth itself, diagnosis of the disability, periodic evaluations, the beginning of a program or school, additional births, adolescence, and emancipation continue to force the family to deal again and again with the shock of having a retarded child.

Wolfensberger (1967) presented three types of family responses resulting from the presence of a mentally retarded child: 1) the Novelty Shock Crisis, 2) the Crisis of Personal Values, and 3) the Reality Crisis. He states, "Some parents experience all of these, others one or none. The crises may occur simultaneously, but to some degree they will tend to correlate with the age of the child." Any of the above family developmental milestones can potentially send a family back to face one or all of these crises. The therapist, after assessing the crisis with which the family is struggling, will need to design interventions to aid the family's return to equilibrium.

Case Study

> Mrs. S.'s eight year old son, Bill, had been given a diagnosis of "mental retardation". When she came to the clinic for an updated evaluation, Mrs. S. was especially concerned about his lack of language development and excessive drooling. Mrs. S. had hoped the clinic staff would have an appliance to aid Bill's speech development. Instead, evaluations indicated no appliance would be

> able to aid speech. Mrs. S. felt confused, helpless, out of control, and extremely angered by impressions and recommendations that did not support her expectations.

Mrs. S. was confronted with the novelty shock described by Wolfensberger. Previous evaluations, interpretations, and interventions had not penetrated her denial of reality. Medical interpretation was sought to address Mrs. S.'s belief that additional intervention such as surgery could correct the condition in her son. Initial therapeutic intervention with Mrs. S. was primarily supportive in nature to aid in the realignment of her expectations. Bill's drooling was of special concern to her as she was repulsed by it, but was continually confronted with it. The drooling was a source of continued insult, and posed a threat that she might reject Bill even though she had an extremely close relationship with him. Therapeutic intervention was also needed to address the ambivalence she felt toward Bill. Planning and provision of program services, as well as involvement with parents of other disabled children were also significant needed interventions with this family.

It was anticipated that future events in the S. family's life cycle would again necessitate family intervention. Prolonged family tensions and any repeated interactional patterns which would prove dysfunctional would need to be explored.

Hierarchial Structures

The hierarchial order of the family with a mentally retarded child is often quite confused, with generational boundaries and

role assignments of members being transparent, blurred, or overlapping. Generally when this is the case, one or both of the following has taken place: 1) mother or father has relinquished his or her role as head of the family, or, 2) professionals have taken over parental responsibilities, with or without the parents' consent. In the first instance one or both parents may relinquish their appropriate hierarchial position in the family either through over-involvement or under-involvement with their child. Parents who are over-involved have lost perspective on functional parenting roles and responsibilities, and generational boundaries between parents and child have become blurred. Often the child's disability totally consumes the parents' lives, and financial, time, energy, and emotional resources are severely taxed in order to meet the child's needs. Little energy may remain for the parents to meet their own needs as individuals or as a couple separate from their child. The child's disability becomes the parents' disability and the problems, frustrations, and limitations of the parents and child become the same. If the child becomes arrested developmentally, so does his parent. Ridicule and teasing of the disabled child by schoolmates may be personalized by the parent, and consequently the parent can provide neither direction nor support to the child. Thus the parent cannot facilitate the child's growth in problem-solving skills or aid his movement toward increased independence.

Case Study (Continued)

> Bill reported he was often picked on by his friends because "I walk funny and can't talk good." Mrs. S. had tears in her eyes as she listened and confirmed what Bill said. She reported she gets "real angry" and told the friends if they did it again she would "smack 'em."

Mrs. S. was not able to separate Bill's feelings from her own. She had in fact taken on Bill's affect and his problem-solving responsibilities, denying him the opportunity to deal with his own problem. Any intervention must deal with the sadness Mrs. S. is feeling and with methods for Bill to manage his problems with support from his mother.

The under-involved parent on the other hand may have vacated his position in the family either by rejection of his retarded child or as the result of a negative cycle of interaction with the child. Here the quality of parent-child bonding may be a primary treatment issue. As a result of the child's disability, certain stimuli may be elicited which are distorting the interactional patterns of mother and child and interfering with the child's developmental progress. There may be little psychological reward for parent investment of self, and thus the family may be at-risk for a negative uninvolved cycle of interaction to develop.

Parents are often not seen as equal partners in the endeavor to provide for the child, and if the parents have not been included as equal members in the intervention, many unrealistic fears and concerns may not be resolved. Professionals may take

over parental responsibilities as the result of a mutual "agreement" with parents who are looking for guidance in managing their child. This "expert syndome" is then encouraged by both parents and professionals. Initially parents are often bewildered and uninformed about the needs of their retarded child, and professionals may then begin to assume parental responsibilities. Problem solutions are sought <u>for</u> the family as opposed to <u>with</u> the family, fostering dependence on the professional, and supporting a notion parents may already have that they are inadequate.

The therapist working with families in which hierarchial structures have been altered directs the family in clarifying roles and re-establishing clear generational boundaries. Parents are encouraged to evaluate conflicting messages they may be giving their child about growth and independence. The professional may need to communicate to the parents that they are in charge of their family as well as of their own individual needs. Support is given and tasks are assigned which allow for and encourage increased differentiation of parent and child, and which demonstrate the appropriate roles of each.

The Central Triangle

The most common interactional pattern of concern associated with the presence of a mentally retarded child in a family is the development of a dysfunctional "central triangle" involving mother, father and disabled child. Structurally, such dysfunction may not be unlike that in any family system. Generally speaking, the presence of such children does not drastically affect the

basic interactional pattern, but the child's presence will often tend to magnify already existing patterns and exacerbate pre-existing dysfunctions. It is critical for the therapist to determine if there was dysfunction in the executive system prior to the presence of the disabled child and if so, how long and to what degree the pattern has operated in a family. It is also important to note if the family focus has simply shifted from one problem to another. The family with a mentally retarded child may thus present a combination of problems in place prior to and then compounded by the child's presence.

Following are three diagrams of family dysfunction commonly found in families with mentally retarded children (Figure 1). In Diagram 'A' both parents are over-involved with the disabled child to the detriment of the marriage relationship. The presence of the child's disability permits the focus to remain on the child and off the marital relationship. The financial, physical and emotional demands generated by the child's presence may have forced additional parental involvement, thus detracting from the marital subsystem. In this instance the clinician will need to aid the parents in disengaging from the child and in establishing or re-establishing a functional marital subsystem.

In Diagram 'B' the child and one parent are over-involved, with the other parent remaining isolated or peripheral. In families with a disabled child the over-involved parent is more likely to be the mother, in part because the mother may have primary responsibility for maintaining appointments with doctors,

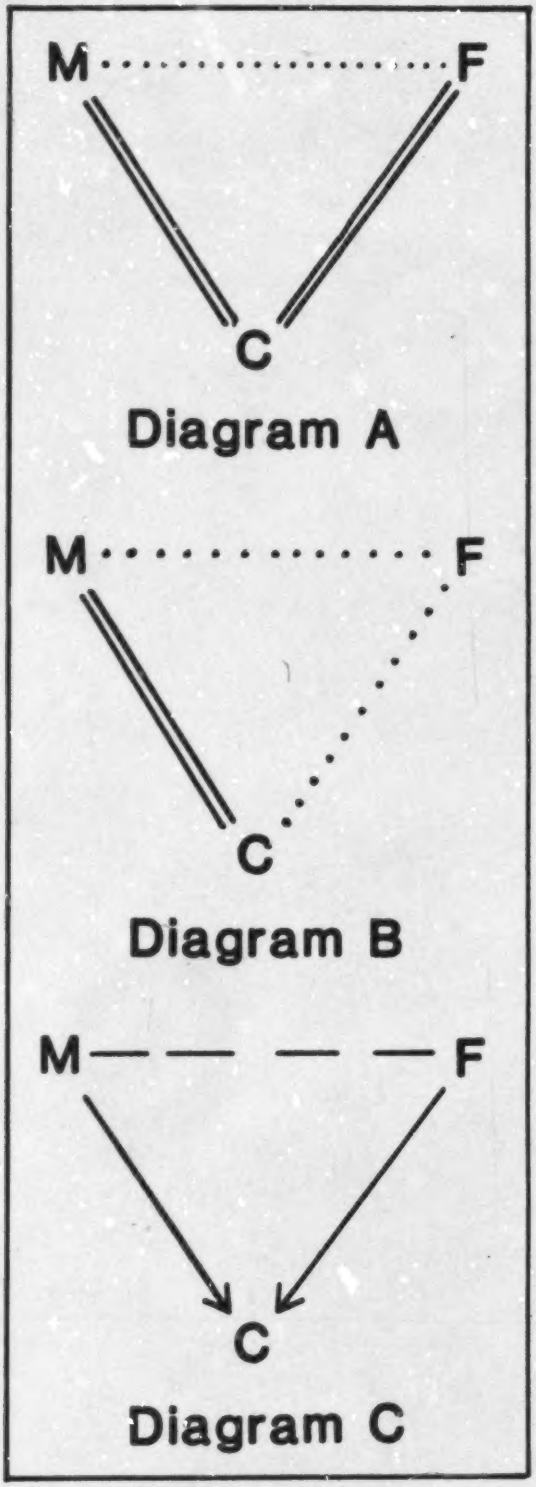

FIGURE 1

therapists and other professionals, appointments which are usually made during normal working hours, and which preclude the possibility of ongoing involvement between the father and professionals. Too, the mother usually has the responsibility for implementation of professional recommendations, and for re-interpretation of the findings and recommendations to her husband. Re-interpretation requires a great deal of energy on the part of the reporting parent, forced to deal again with traumatic reminders of the child's condition. Need for secondary gain in such an interactional pattern may allow the mother to maintain a passive-aggressive posture about her seemingly enforced position as family representative. This posture may encourage the father to maintain his peripheral position and further enable him to remain unconfronted by his child's disability. If the marital subsystem is not strong, the sharing may not take place, thus reinforcing existing dysfunctional patterns. In this instance the therapist's task is to devise strategies to engage the peripheral parent with the child and to aid in establishment of a functional marital subsystem.

Diagram 'C' illustrates a pseudo-alliance between the parents. In this model, marital problems are avoided by the parents uniting for the sole purpose of focusing attention on the child. In this "detouring" process, the child may be either protected or scapegoated by his parents. The fragile child in this family model is portrayed by his parents as pathetic and vulnerable, and in need of protection, while the scapegoated

child is portrayed in fact as the source of all family problems. Here the task of the clinician is to remove the primary focus from the child and shift it back to the marital subsystem.

Each diagram illustrates a dysfunctional pattern of interaction. In every case the primary treatment intervention goals are to facilitate the formation of a functional marital subsystem and to establish the parents as effective heads of the family hierarchial structure, including but not focusing upon the retarded child.

SUMMARY

Problems confronting the family with a mentally retarded child continue to present unique clinical issues for the professional. The current emphasis on rights and services for retarded children, representing major shifts in philosophical thinking, has challenged these professionals to develop community-based treatment approaches in which the child is served at home. The impact of such children upon the evolving family system such as the specific family dynamics, parent-child relationships, and the issues of family developmental adjustment to the presence of the child must be major considerations in a family-focused treatment approach. The professional must seek, through restructuring of the family hierarchy and family role assignments, to foster the development of functional, intrafamilial relationships.

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